

Virginia Genetics Advisory Committee
Monday, June 23, 2003
1:00 p.m. - 3:00 p.m.

Virginia Department of Health
1500 East Main Street
Richmond, Virginia 23219
3rd Floor Conference Room
Telephone: 804-786-7367

MINUTES

Present: Willie C. Andrews—DCLS; Lynette Bartlett, LPN—VDH; Joann N. Bodurtha, MD, MPH, Chair—VCU; Nancy Ford, MPH, RN—VDH; Sara Long—March of Dimes Va. Chapter; Virginia K. Proud, MD—CHKD; Jene O. Radcliffe-Shipman—VDH; Suzanne Trotter, MS, RN—VDH; Sharon Williams, MS, RN—VDH; William G. Wilson, MD—UVA Health Sciences Center; Melody Persinger Yeargin—CHKD; Joanne S. Boise, MSPH—VDH (Ad Hoc member)

Guests: Carrie Townsend—March of Dimes, Summer Intern; Katie Teague—VCU, Genetics Needs Assessment Project Manager.

Absent: Nancy Bullock, RN, MPH—VDH; Laura Duncan, MPH, RD—VCU; Kathleen M. Link, MD—Inova Fairfax and Fairoaks Hospitals; Karen Meister, MS, CGC—VCU/VDH; Walter Nance, MD, PhD—Va. Newborn Hearing Screening Cmt.; Arti Pandya, MD, MBA—VCU; James L. Pearson, DrPH—DCLS; Gwen Smith, RN, MSN—VDOE; Harvey Stern, MD, PhD—Genetics and IVF Institute; Charlie Stevenson, MS—DCLS; Joan Corder-Mabe, RNC, MS, OGNP—VDH (Ad Hoc member)

Recorder: Nancy Ford

Time	Item	Person	Notes/Plan
1:00 to 1:15	1. Welcome a. Introductions b. Approval of 10/29/02 Minutes c. Review of Agenda	J. Bodurtha	a. Paul B. Kaplowitz, MD, PhD—VCU is no longer a member; Mary Ann Discenza, Part C Coordinator, DMHMRSAS has replaced Anne Lucas. b. Approved as written. c. No changes.
1:15 to 1:30	2. Agency & Grant Updates a. VDH: Virginia Genetics Program b. VDH: Virginia Sickle Cell Awareness Program c. DCLS d. VDH: CDC Grant “Va. Congenital Anomalies Tracking and Prevention Improvement Project” e. VCU: MOD Grant “	a. S. Williams b. J. Shipman c. J. Pearson d. K. Meister e. J. Bodurtha f. V. Proud	a. SFY 04, which begins 7/1/03, is the last year of 5-year contracts for genetic centers and metabolic centers. Contractors concerned that final MOA will not be received before start date. Quarterly reporting system for genetic centers will be required in SFY 04. Plan: <ul style="list-style-type: none">• S. Williams will send letter of intent to fund.• S. Williams will send quarterly report to contractors for comments. b. The following items were distributed

	<p>Genetic Services and Education-Assessment of Needs”</p> <p>f. EVMS: CDC Grant Application “Genetic Services for Infants with Congenital Hearing Loss in Va.”</p>		<p>and briefly reviewed: “Virginia’s Sickle Cell Program”, Virginia Sickle Cell Awareness Program—DWIH, VDH”, “Summary: ‘Sickle Cell Treatment act of 2003’ (S.874/1736”, and “Who Is Florence Neal Cooper Smith?”</p> <p>c. On 6/9/03, state and local officials dedicated a new consolidated laboratories building at the Virginia Biotechnology Research Park in Richmond. Sought and received letter from AG Office that DCLS newborn screening services are exempt from HIPAA.</p> <p>d. Yr-2, which began 3/1/03, has been fully funded. DWIC/NCS is in process of hiring the VaCATPIP Va. Folic Acid Campaign Manager. Continue to make QA improvements in VaCARES reporting processes via VISITS.</p> <ul style="list-style-type: none"> • Objectives: (1) Assess current status of genetic services, education, and barriers to care in Va. using existing data; (2) Initiate the assessment of current and emerging practices and deficiencies within genetic health services and education delivery in Va. by interviewing genetic service providers; (3) Evaluate the needs assessment literature review and interview information; and (4) Initiate literature review and genetic provider interview summaries with March of Dimes and key stakeholders. The “Genetic Provider Survey” draft was distributed and reviewed. <p>e. Objective: The project will study newborns with hearing loss identified in Va. to assess the reason why patients are/are not being referred for genetics evaluation, timeframe of referral, effectiveness of genetics’ evaluation services, and experience of the newborns’ parents/legal guardians. Application has been sent; notice of awards will be made by end of July.</p>
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1:30 to 1:45	3. Genetic Centers Updates a. VCU b. EVMS c. UVA d. RFP Northern Virginia	a. J. Bodurtha b. V. Proud c. B. Wilson d. S. Williams	a. Continuing education and collaborative office rounds grant has started with good response from community pediatricians. b. Outreach perinatal programs are being consolidated. Two new genetic counselors replace two that resigned. c. Several successful parent group activities (e.g., PKU Day, PKU Annual Picnic) have been held. Added dates to genetic clinics to keep waiting period below one month. d. An RFP was initiated because there are no comprehensive genetic centers in northern Va.
1:45 to 2:15	4. Finalize Facilitator's Report and Confirm VaGAC Decisions from October 29, 2002 Meeting a. Mission b. Work Groups c. Membership d. Other Organizational Decisions • Steering Committee • Chair • Meeting Schedule • Decision-Making and Quorum • Communication Tools e. Revised Report	J. Bodurtha with group discussion	a. Mission modified: "literacy" replaced with "awareness" and "individual consent" changed to "consent". b. 4 th group added: VDH Contractors. Plan: • <u>S. Williams</u> or designee will convene a "Contractors Only" work group. c. Discussed merits of adding new members. Plan: • <u>All Work Groups Conveners</u> will expand membership as appropriate and will invite to large group meeting as appropriate. (See Facilitator's Report for membership suggestions.) d. Will remain in place as described in Facilitators Report. e. Plan: <u>N. Ford</u> will prepare a condensed summary report with today's revisions, entitled "VaGAC Infrastructure", which can be updated at each meeting.
2:15 to 2:30	5. Committee and Work Groups Reports a. Steering Committee b. Parent Involvement Work Group c. State Genetics Plan Work Group d. Tandem Mass Spectrometry Work	a. J. Bodurtha b. J. Bodurtha for K. Meister c. J. Bodurtha d. W. Andrews	a. Steering Cmt: Has met one time, developed today's agenda. Plan: • <u>N. Ford</u> will convene before next VaGAC meeting to develop agenda. b. Parent Involvement WG: Had a brainstorming session meeting with parents. Requested VaGAC support

	<p>Group</p> <p>e. Contractors Work Group (new)</p>		<p>parent advocacy training. S. Long reported that MOD offers such training annually.</p> <p>Recommendation:</p> <ul style="list-style-type: none"> • Connect with MOD training when appropriate. <p>c. State Genetics Plan WG: The foundation of the State Genetics Plan will be the statewide needs assessment (see item 13, MOD grant) and the strategic planning in PSGS, their overlap and unique aspects.</p> <p>Plan:</p> <ul style="list-style-type: none"> • <u>All members</u>--Please give comments on the draft of the genetic provider survey to katherineteague@hotmail.com or bodurtha@hsc.vcu.edu by June 27. <p>d. MS/MS WG: Moving forward toward implementing MCAD deficiency screening by March 2004. Parent review of educational materials would be helpful. Recommendations:</p> <ul style="list-style-type: none"> • Involve Va. Hosp. Ass'n, Va-AAP, and MCOs in work group. • Announce plans in professional association newsletters early. • Announce implementation via VDH Press Release. <p>e. Contractors WG: Request made to form this work group, which would be comprised of VDH contracted genetics and metabolic centers and convened by S. Williams</p>
2:30 to 2:45	<p>6. New Business</p> <p>a. Request for Public Input: Virginia's Title V/MCHB Block Grant Application</p> <p>b. VaCARES 1989-1998 Report</p>	J. Bodurtha	<p>a. Request, which was emailed previously, was distributed. Members encouraged to respond.</p> <p>b. Please return Report Feedback Form, which is in Appendix F.</p>

2:45 to 3:15	7. Large Group Adjourns and Work Group Sessions Begin a. Next Meeting: Date, Time, Location, Focus b. Work Group Sessions <i>(This time is available for work groups to meet and plan. In addition, if work groups would like to meet longer, the room is available until 5 p.m.)</i>	a. J. Bodurtha b. Work Group Conveners	Next VaGAC Meeting: <ul style="list-style-type: none">• Date: Monday, September 29, 2003• Time: 10 a.m. – 12 noon• Location: Division of Consolidated Laboratory Services, 600 North 5th Street, Richmond, VA 23219• Telephone c/o W. Andrews: 804-648- 4480, ext. 153• Focus: Updates, work group reports, Sickle Cell trait follow-up update. <p>Note: Before the meeting, there will be an optional tour of the new DCLS facility from 9 a.m. – 10 a.m.</p>
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